

Disease-related social situation in family of children with chronic kidney disease – parents' assessment. A multicentre study

Katarzyna Kiliś-Pstrusińska¹, Anna Medyńska¹, Piotr Adamczyk², Irena Bałasz-Chmielewska³, Ryszard Grenda⁴, Agnieszka Kluska-Jóźwiak⁵, Beata Leszczyńska⁶, Ilona Olszak-Szot⁷, Monika Miklaszewska⁸, Maria Szczepańska², Marcin Tkaczyk⁹, Anna Wasilewska¹⁰, Katarzyna Zachwieja⁸, Maria Zajączkowska¹¹, Helena Ziółkowska⁶, Ilona Zagożdżon³, Danuta Zwolińska¹

¹ Department of Paediatric Nephrology, Wrocław Medical University, Poland

² Clinic of Paediatrics, Nephrology and Endocrinology, Silesian Medical University, Zabrze, Poland

³ Department of Pediatric & Adolescent Nephrology & Hypertension, Medical University of Gdańsk, Poland

⁴ Department of Nephrology, Kidney Transplantation and Hypertension, The Children's Memorial Health Institute, Warsaw, Poland

⁵ Department of Pediatric Cardiology and Nephrology, Poznań University of Medical Sciences, Poland

⁶ Department of Pediatrics and Nephrology, Medical University of Warsaw, Poland

⁷ Department of Nephrology, Children Hospital, Toruń, Poland

⁸ Polish-American Children's Hospital, Jagiellonian University, Kraków, Poland

⁹ Nephrology Division, Polish Mother's Memorial Hospital Research Institute, Łódź, Poland

¹⁰ Department of Pediatrics and Nephrology, Medical University of Białystok, Poland

¹¹ Department of Pediatric Nephrology, Medical University of Lublin, Poland

Kiliś-Pstrusińska K, Medyńska A, Adamczyk P, Bałasz-Chmielewska I, Grenda R, Kluska-Jóźwiak A, Leszczyńska B, Olszak-Szot I, Miklaszewska M, Szczepańska M et al. Disease-related social situation in family of children with chronic kidney disease – parents' assessment. A multicentre study. *Ann Agric Environ Med*. 2014; 21(4): 876–881. doi: 10.5604/12321966.1129951

Abstract

Introduction and Objective. Chronic kidney disease (CKD) in children burdens life of patients and their families. Little is known about parents' assessment of families' social situation. However, the knowledge of the details of a patient's and his family's life standards might influence modification and optimization of applied therapy. Therefore, the main goal of the present study was to explore the selected elements of life situation of patients suffering with CKD as well as their parents, depending on the CKD stage and appropriate treatment.

Materials and Methods. Cross-sectional national study was conducted. A total of 203 children with CKD and 388 their parent-proxies (196 women and 192 men) were enrolled into this study. Patient data and questionnaires filled by both parents, concerning social-demographic parameters and assessment of changes in families after CKD diagnosis in the child, were analysed.

Results. CKD children are being brought up in proper families whose financial situation is not good. Children need help in process of education. Perception of current situation differed between both parents in the change of the income source, taking care of CKD child, change in social relations and evaluating relations with medical staff. Parents do not obtain proper support from social workers.

Conclusion. Families of CKD children require support in area of financial and educational help for school children. The discrepancies in evaluation of family situation between mothers and fathers of ill children might be the source of conflicts possibly resulting in worsening the outcome for CKD children.

Key words

family, chronic kidney disease, children and adolescents, socioeconomic factors

INTRODUCTION

Chronic kidney disease (CKD) and its consequences are a public health concern [1]. The aim of CKD management is not only the improvement or substitution of kidney dysfunction, together with eliminating corresponding general health disorders, but also providing the patients suffering from the disease a suitable quality of life. CKD creates a difficult situation, not only for a CKD child but also for the family, which is very important for the child [2, 3, 4]. The family creates the first, basic and sometimes the only social environment for the young growing patient.

Parents – in addition to typical parental responsibility and activities giving support appropriate to a child's age – must be engaged in the therapeutic process. Their activities, including cooperation with medical staff, could be crucial to the quality of their child's life determined by the disease. They 'adapt' the role of people providing medical care. Their attitude depends on their health condition as well as perceiving their situation, including social and economic standards.

To date, no full analysis of the disease-related social situation in children with CKD in Poland has carried out. There are also not many foreign publications in this field which take into consideration the local social-economic context [5, 6]. However, knowledge of the details the standards of life of patients and their families might influence the modification and optimization of the therapy applied. Therefore, the main goal of the presented study is to explore

Address for correspondence: Katarzyna Kiliś-Pstrusińska, Department of Paediatric Nephrology, Wrocław Medical University, Borowska 216, Wrocław, Poland
E-mail: katarzyna.kilis-pstrusinska@umed.wroc.pl

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the selected elements of the life situation of patients suffering with CKD, as well as their parents, depending on the CKD stage and appropriate treatment. How the parents evaluate changes in social functioning after the illness of their child had been recognized is also analyzed.

MATERIALS AND METHOD

Participants. Eleven out of 12 paediatric dialysis centres in Poland took part in a cross-sectional study. The research was conducted with children with CKD, as well as with their parent-proxies, between September – December 2011. The study protocol adhered to the Declaration of Helsinki and was approved by the Ethics Committee of the Medical University in Wrocław, Poland. The parents of all the patients and the children over 16 years of age gave their written informed consent. Verbal assent was obtained from patients under 16-years-of age whenever possible.

The criteria for including the children were:

- 1) aged 2 or older;
- 2) stage II of CKD or higher (according to KDOQI Guidelines) on the basis of estimated glomerular filtration rate (eGFR) by the Schwartz formula [7];
- 3) CKD diagnosed at least 3 months previously;
- 4) informed consent.

Exclusion criteria for children:

- 1) history of severe to profound mental retardation;
- 2) renal, other solid-organ, bone marrow, or stem cell transplantation;
- 3) cancer/leukaemia diagnosis;
- 4) hospitalization within 14 days (excluding the hospitalization due to haemodialysis or peritoneal dialysis control);
- 5) initiation or change of dialysis modalities within the past 30 days;
- 6) experiencing a significant life event unrelated to the kidney disease in the past 30 days (loss of a family member).

A medical chart review was performed to obtain the following information: primary diagnosis of kidney disease, age of CKD diagnosis, duration of illness, time of nephrology control, presence or absence of significant non-renal comorbidities and family history. Size of the children's place of residence was also taken into consideration. For school-age children, interviews of the patient or parents were conducted to determine the child's schooling level, and whether the child required special education (supplementary tutoring or an individualized education programme).

The parents were asked to fill in questionnaires (one questionnaire for each mother and father) concerning some social-demographic parameters. Next, the parents answered the questions referring to changes in their family after diagnosis of CKD in the child. The questionnaire was created by physicians and psychologists dealing with CKD children, and based on their own experience and literature data.

Data analysis. A staged approach was used to identify many demographic, socio-economic and health status variables associated with the disease-specific situation in CKD children and their parents. The CKD children were divided into 3 groups depending on the treatment modality: conservative treatment (CT), haemodialysis (HD) and peritoneal dialysis (PD). First,

the data was analysed generally and then in a more detailed way, depending on CKD stage and methods of therapy. The mean differences were evaluated between the mentioned CKD groups and compatibility assessed between the mother's and the father's perceptions of changes in family life.

Statistical analysis. Statistical analyses were performed using R for Windows, version 2.15.1 (The R Foundation for Statistical Computing, Vienna, Austria) and MedCalc for Windows, version 12.3.1.0 (MedCalc Software, Mariakerke, Belgium). Means, standard deviations, medians, interquartile, frequencies and percentages were reported to describe the data, as appropriate. Qualitative variables were presented as numbers and percentages. The chi-squared test or Fisher's exact test were used for comparison between groups. Quantitative variables were tested for normality distribution by Kolmogorov-Smirnov test. For comparison between groups the Mann-Whitney test, the Student's *t* test and the Kruskal-Wallis test were used, as appropriate. P-values of less than 0.05 was considered statistically significant.

RESULTS

A total of 203 children with CKD and 388 parent-proxies (196 women and 192 men) were enrolled into the study. The basic characteristics of 591 study participants are shown Table 1 and 2. Missing data of parents concerned 7 mothers (4 were dead, in cases of 3 children in social care homes there

Table 1. Basic characteristics of CKD children

	n	%
Age, mean \pm SD, years	10.95 \pm 4.95	
Gender		
female	80	39
male	123	61
Cause of CKD		
chronic glomerulonephritis	32	15.8
chronic pyelonephritis (CPN)	15	7.4
anomaly of kidney and urinary tract and CPN	45	22.2
anomaly of kidney and urinary tract	42	20.7
hereditary kidney disease	34	16.7
others	23	11.3
unknown cause	12	5.9
Comorbidity		
yes	34	16.8
no	169	83.2
Family renal history		
yes	27	13.3
no	176	87.7
Place of residence (size)		
village and town < 50, 000 inhabitants	88	43.4
town 50, 000 – 100, 000 inhabitants	51	25.1
town > 100, 000 inhabitants	64	31.5
Hypertension		
yes	110	54.2
no	93	45.8
Age of CKD diagnosis, median (quartiles), years	2.02 (0.17; 8.0)	
CKD duration, mean \pm SD, years	6.91 \pm 4.8	
Time of nephrology care, years	6.41 \pm 4.52	
CKD treatment modality		
Conservative treatment	137	67.5
Haemodialysis	25	12.3
Peritoneal dialysis	41	20.2

Table 2. Basic characteristics of parents and family of CKD children

	n	%
Mothers	196	100
Age, mean \pm SD, years	37.97 \pm 6.74	
Mother's education level		
elementary / trade school	87	44.4
high school	72	36.7
university degree	37	18.9
Employment		
Yes	129	61.2
No	67	38.8
Healthy		
Yes	165	83.3
No	31	16.7
Fathers	192	100
Age (mean \pm SD), years	40.91 \pm 7.39	
Father's education level		
elementary / trade school	124	64.6
high school	42	21.9
university degree	26	13.5
Employment		
Yes	165	86
No	27	14
Healthy		
Yes	164	85.4
No	28	14.6
Family		
Full	175	86.2
Single-parent family	25	13.8
Sibling		
Yes	163	80.3
No	40	19.7

was no contact with parents) and 11 fathers (2 were dead, in 3 cases the children stayed in social care homes, and in other cases, there was no contact with the father: 'for the family, the father does not exist').

Patients. Of the patients, 25 (12.3%) were on HD, 41 (20.2%) on PD and 137 (65.5%) received CT (CKD \geq stage II). Among the last group of children, 30 (22%) was at stage II of CKD, 58 (42%) – at stage III, 40 (29%) – at stage IV and 9 (7%) – at stage V without renal replacement therapy (RRT). In most cases, CKD had been recognized in early childhood. Mean CKD duration was 6.91 ± 4.8 . The average time of staying under the care of a nephrologist was 6.41 ± 4.52 . The differences in periods of nephrological care in the distinguished groups of children were insignificant (data not shown).

Among school-aged children, 68 (44.1%) attended elementary school, 56 (36.4%) – junior high-school 26 (16.9%), 15 (9.7%) – high-school, 8 (5.2%) – trade-oriented high-school and 3 (2%) to trade schools. 30 % of children were under an individualized education programme, the others under a regular programme. Among the PD children, individual tuition was given in 55.2% versus 66.7% of HD, versus 17.4% conservatively treated. There was a statistically significant difference in the way of teaching between CT and dialysis patients ($r=0.7$; $p<0.01$). The kind of dialysis was not disputed, however. 161 patients answered the question regarding help in learning. More than half of the respondents (95 (59%)) used different kinds of help, among them 88 (54.7%) were supported by parents and/or siblings, 4 children (2.5%) had tutors, 3 children (1.8%) were being helped in both ways. The differences between the CKD groups were insignificant.

Families of children with CKD. Data shown in Table 2. The majority of the patients are being brought up in full families, i.e. the patient and both parents. No differences were noted in family structure between the patients treated in a different way.

There was a significant statistical difference between the education of mothers of the HD children (mainly elementary or trade school education, 37.5% and 29.17%, respectively) and of those treated with PD (mostly high-school education or with a university degree, 37.5% and 29.5%, respectively) ($p=0.017$). The majority of mothers were not employed. No significant differences were shown in these areas depending on treatment methods. Almost all mothers (194, i.e. 99%) lived with their sick children; 2 mothers who were taken into consideration in the study lived separately, and the child was taken care of by the father. In the fathers' group, no differences in education level were noted between subgroups concerning modality treatment of their children. 90.63% (174) fathers lived with children suffering from CKD, 18 (9.37%) did not.

Most children with CKD had siblings (average age 14 ± 8.82). Most often, the CKD children had one brother/sister (83, i.e. 40.89%) or two siblings (42, i.e. 20.69%). The number of people cohabiting in the families did not differ in groups of CKD children. The residences of the families were not big. In 130 families (65%) the number of rooms was from 1–3: 8 families – 1 room (4%); 55 families – 2 rooms (27.5%); 67 families – 3 rooms (33.5%). In the remaining 70 families (35%) the number of rooms was from 4–10.

The main livelihoods of the families were as follows: employment – 103 families (51.5%), retirement – 4 (2%), employment plus retirement/pension – 12 (6%), employment plus social care – 48 (24%), retirement/pension – 9 (4.5%), social care – 24 (12%). 81 families (40.5%) used social care which was their vital source of living. For 12% of the families it was the only source of living. In the families of PD or of CT children, parents' employment, to a higher degree, was the source of living than in HD (82.5% vs. 84.73% vs. 60%, respectively; $p=0.01$). The latter group of families used social care and support more often than the other groups (30.0% vs. 32.3% vs. 60%, respectively; $p=0.009$).

Parents' assessment of changes in family life after CKD diagnosis in their child. Parents noticed changes in their lives after the children had been diagnosed with CKD (Tab. 3). Noticing the changes in their own life situation by mothers and fathers in most cases was not connected with the type of the child's treatment. Exceptions: 60% of mothers and 51.2% fathers of the children treated with PD reported changes in their apartments, versus 20.3% of mothers and 13.6% fathers of CT children and 12.5% mothers of HD patients ($p<0.001$).

No significant differences were reported in noticing the changes in attitude to the sick child and his/her siblings, depending on CKD modality. However, there is certain tendency to report a more positive attitude to a sick child by mothers of PD or CT children than of HD children. No significant relationship was reported between the way of treating the patient and the mother's perception of the relationship among her children.

It was noted that the perception of deteriorated social contacts was the highest among the mothers of PD children (PD: 60%; HD: 43%; CT: 34%; $p=0.02$). That group of mothers also reported making new social contacts (PD: 70% vs. HD: 52% vs. CT: 42%; $p=0.007$).

Table 3. Changes in the family after diagnosing the child with CKD being noticed by his/her parents

	Mother evaluation n = 196		Father evaluation n=165 [^]		p
	Yes n %	No n %	Yes n %	No n %	
Place of residence	23 11.73	173 88.27	17 10.3	148 89.7	0.79
Changes in current place of residence	55 28.06	141 71.94	38 23	127 77	0.33
Change of financial status: deterioration	91 46.43		70 42.4		
improvement	84 42.86	105 53.57	65 39.4	95 57.6	0.51
	7 3.57		5 3.0		
Change of source of income	54 27.55	142 72.45	23 14	142 86	0.002
Care of child:					
mother	148 75.51		75 45.5		0.001
father	3 1.53		7 4.2		
both parents	45 22.96		83 50.3		
Participation of other people in child care:					
grandparents	86 42.86		63 38.2		0.37
siblings	69 35.2	112 57.14	50 30.3		
cousins	14 7.14		13 7.9	102 61.8	
friends	4 2.0		3 1.8		
	3 1.5		1 0.6		
Change of attitude to the child:					
improvement	73 37.25		50 30.3		0.2
deterioration	70 35.70	123 62.75	48 29.1	115 69.7	
	3 1.5		2 1.2		
Change of attitude to other children:					
improvement	*25 16.0		*24 15.3		1
deterioration	23 14.7	132 84.0	20 12.8	133 84.7	
	2 1.3		4 2.5		
Change of relations among children:					
improvement	*28 17.9		25 15.9		0.76
deterioration	26 16.6	129 82.1	23 14.6	132 84.1	
	2 1.3		2 1.3		
Change in social contacts:					
improvement	86 43.88		58 35.2		0.11
deterioration	6 3.06	110 56.12	3 1.9	107 64.8	
	80 40.82		55 33.3		
New contacts	98 50	98 50	51 31	114 69	0.0003

*n=157

[^] the data included from 165 surveys.

The missing surveys (27; 14%); 11 fathers – no contact (they do not live in the same household); 14 fathers did not fill this part of survey; 2 surveys were filled only partially.

Each parent was asked to evaluate the relationship with people from the closest environment, and with medical staff, awarding points from 1 (very bad) to 5 (very good) (Tab. 4). The answers of both parents were then compared (Tab. 5).

Table 5. Mothers' and fathers' evaluations of relations with other people – differences

	p
Mother/father of the child	0.13
Child with CKD	0.16
Other children	0.13
Friends	0.08
Nurses	0.02
Doctors	0.003
Social workers	0.28

Statistically significant differences (p<0.05) are shown in bold

In the group of mothers, no changes in their evaluation of relations with the child's father, the child or its siblings were reported, depending on the CKD treatment modality. Mothers of HD children rated the social relations higher than the mothers of CT children and of PD patients (estimated as 5 in group of mothers: HD 47.8% vs. PD 31.7% vs. CT 31.2%; p=0.01).

A significant difference was reported in the estimation of the relationship with nurses, depending on the type of treatment. The relationships were rated with '5' by 82.6 % of HD mothers, by 58.5% of PD mothers and by 38.9 % of CT mothers (p<0.001). No significant differences were reported among groups of mothers in their estimation of their relationship with doctors. Mothers of HD children evaluated social workers relatively higher than mothers of PD and CT patients.

Estimating their current knowledge on their children's disease, 40 (20.1%) of mothers described it as average, 120 (61.2%) as good and 36 (18.7%) as very good. None of the mothers described her knowledge as poor. According to only 49 mothers (25%), information on their children's disease was insufficient at the time of its recognition. No differences were noted in estimating the information depending on method of treatment.

Regarding fathers, the current knowledge on their children's disease was poor in 19 (11.5%) cases, it was average in 54 (32.7%) cases, 80 fathers (48.5%) described it as good and 12 (7.3%) as very good. According to 57 fathers (34.5%), the information on their children's disease at the time of its recognition was insufficient, whereas for 108 fathers (65.5%) it was sufficient.

In each family, the parents indicated one main person responsible for taking care of the sick child. In most cases

Table 4. Evaluation of relations of parents with other people (No. of responses, (percent))

	Mother						Father					
	N*	1	2	3	4	5	N*	1	2	3	4	5
Father/ mother of a child	189	12 (6.3)	3 (1.6)	15 (8)	59 (31.2)	100 (52.9)	165	3 (1.8)	7 (4.2)	10 (6.2)	56 (33.9)	89 (53.9)
Child with CKD	196	0	2 (1.0)	5 (2.5)	40 (20.5)	149 (76)	165	1 (0.6)	1 (0.6)	5 (3.0)	49 (29.7)	109 (66.1)
Other children	158	0	1 (0.6)	2 (1.3)	45 (28.5)	110 (69.6)	134	1 (0.75)	1 (0.75)	7 (5.2)	43 (32.1)	82 (61.2)
Friends	194	4 (2.1)	9 (4.6)	42 (21.6)	74 (38.2)	65 (33.5)	165	1 (0.6)	5 (3.0)	22 (13.3)	82 (49.7)	55 (33.3)
Nurses	195	0	2 (1)	13 (6.6)	85 (43.6)	95 (48.7)	132	5 (3.8)	2 (1.5)	16 (12.1)	55 (41.7)	54 (40.9)
Doctors	195	1 (0.5)	2 (1)	8 (4.2)	65 (33.3)	119 (61)	131	5 (3.8)	0	14 (10.7)	52 (39.7)	60 (45.8)
Social workers	195^	6 (3.1)	4 (2.1)	17 (8.7)	43 (22.1)	43 (22.1)	165#	5 (3)	8 (4.9)	11 (6.7)	26 (15.7)	21 (12.7)

* For respective categories different number of answers was obtained, therefore they were given (n).

[^] 113 mothers; 82 mothers (42%) have never had any contact with a social worker.[#] 71 fathers; 94 fathers (57%) have never had any contact with a social worker.

– 175 (86%) – it was the mother, in 19 (9.5%) it was the father, in 6 cases both parents were indicated (3%). The main caregivers evaluated the relationship with medical staff using the scales 1–5, rating it '5' in 119 cases (58.6%), '4' in 73 (36%), and '3' in 11 cases (5.4%). 171 main caregivers (84.2%) had no expectations as far as nurses were concerned, but 32 people (15.8%) suggested the following issues: higher level of engagement, understanding and being interested, help at the time of being hospitalized in the ward, and more information about how to treat the sick child. Regarding doctors, 162 main caregivers (79.8%) had no expectations, while 41 (20.2%) usually expected more information about the disease and more time for conversation.

Informing the parents about the course of the illness: 11 (5.4%) people evaluated the language as complicated, compared to 192 people (94.5%) for whom it was understandable. The main place where the people were informed was a doctor's surgery (119 cases, 58.6%); in 74 cases (36.5%) it was a hospital room, in 10 cases (4.9%) – a hospital hall. 22 main caregivers (10.8%) evaluated the time spent on informing the parents as too short, for the remainder it was sufficient. The information submitted and evaluated by main caregivers: according to 137 people (67.5%) it was sufficient, for 48 (23.7%) it was incomplete, and for 18 – insufficient (8.8%). 98 people (48.3%) reported that with the exception the information supplied by medical staff they did not use any other source of information about the disease. The remaining 105 (51.7%) used other sources: 8 people only from Internet, 14 – advice of other parents, 2 from other books, 61 – from a few sources. Altogether, the most often pointed source (treating sources as 100%) was the Internet (enumerated 79 times, 44.5%), followed by: other parents (50 times, 28.0%) and books (49 times, 27.5%)

DISCUSSION

The presented study investigated the disease-related social situation in families of children with CKD. In the examined cohort, the cause of CKD was most frequently caused by congenital anomalies of the urinary system, which is comparable with other European and world registers [8]. Due to the recognition of CKD in the early childhood, the time of the families living with the disease was relatively long, about 6 years. The comparable time of CKD duration and the time of the patient's remaining under nephrological care shows that after recognizing CKD, Polish children are immediately sent to a nephrologist.

Although the life span of CKD children is definitely shorter than of their healthy equals, the time is being lengthened. School education is a vital element to prepare the children for participation in adult life [5, 9, 10]. A highly advantageous phenomenon in the CKD children in the presented study was the fact that almost all of them attended regular, normal schools. The disease causes a number of restrictions which result in the necessity of help in the process of education. This is an obligation of the parents, very few of whom used the help of professional teachers. This might be explained in many ways, including too high costs with respect of the financial situation of the parents [11]. The dialysis modality may also create various educational barriers; however, in this study no difference were shown between HD and PD children with relation to individual tuition. Taking into

consideration the fact that undergoing PD means that the children constantly have to stay within their own home environment, and 'is available', the result might show that schools are not adapted for disabled children. It also suggests that children under dialysis, irrespective of the type, are isolated; however, other studies have shown that PD children followed a school curriculum better than HD patients [3, 12].

The families with a chronically ill child undergo higher stress, which may consequently lead to its disintegration [2, 11, 13]. The conducted study did not show any significant difference in family structure of the studied children when compared to the general structure of families in Poland (full families: 86.2 % and 83%, respectively). Other studies have also not observed that the disintegration of families of children conservatively treated or under dialysis was higher when compared to families of healthy children [14]. In the presented study, it was noted that there was a smaller percentage of ill children (14.8%), when compared to the general Polish population (46%), were being brought up without siblings. In disintegrated families, the ill children more often stayed with the mother (76%). However, the participation of fathers in families with ill children was much higher (24%) than in the general population in which disintegrated families consist of single mothers (90%).

In the presented material, most mothers of ill children, regardless the stage of CKD or the dialysis modality, were not employed, although more than half of them had high-school or university education. The observed higher level of mothers' education of PD children suggests that this factor might influence the decision about the choice of dialysis. In study of Aldrige and al., a negative correlation was shown between the level of education and the fear generated by the disease [11]. From this aspect, the more educated mothers might have fewer concerns regarding the choice of PD treatment.

The financial situation of the researched CKD families was not good. The benefit of social care being paid for the ill child was a vital source of income for 40.5% of the families, while for 12% of them it was the only source of income. The situation of the families with HD children seemed to be especially difficult. It seems that in this group, apart from medical factors, the financial situation could have influenced the type of dialysis chosen.

Recognition of CKD in a child causes changes in the life situation of the family [3, 6, 11, 15]. According to more than 40% of both parents it means a worsening of their financial status. 30% think that the attitude to their sick child changes, almost always, for better. This might be explained by the tightening of relations of a child with the parents, as well as by the game of the defence mechanisms of the 'bitter-sweet' type.

In the presented study, perception of the current situation significantly differed between both parents in 3 categories: change of the source of income (more often observed by mothers), taking care of the ill child, and change in making new social relations. In most cases, the mothers pointed to themselves as the main caregivers; only a few of them assigned this role to the father. In turn, half of the fathers reported that they gave care to the child to the same extent as the mother. Other authors also point out the discrepancies at the perception of taking care of a child which is considered to be the source of family conflicts which might result in worsening of the outcome for CKD children [10].

The presented study shows that the illness of a child changes the social contacts of the parents by 30–40%. Mothers more than fathers noticed the deterioration of social contacts, but at the same time, they pointed to new relationships. The quality analysis, however, showed that the new relationships were restricted to parents of other ill children. Similar observations about the isolation of patients' families have been shown by other authors [3, 11, 16]. The decreasing number of social contacts was mostly stated by the mother of PD children, which might be the result of the 24-hour care of the child, and thus lack of time. However, the parents in the presented study perceived their current relations with people from their environment as good and very good. 'Average' social relations were described by every 4th mother and by every 8th father, which indicates that the social contacts of mothers not only became restricted, but also differed in quality when compared to the contacts of their partners. These discrepancies might create conflicts between the parents.

Mothers and fathers significantly differed with respect to their evaluation of relations with medical staff. Better relations of women with nurses and doctors, as described by women, might be explained by better interpersonal communication and more frequent contact with those enumerated. High 'notes' of the nursing personnel given by mothers of HD children prove that relations improve with the extended time spent together (mothers come to dialysis centres and spend most of the time with nurses when their children are undergoing dialysis).

The presented results show that the parents of CKD children do not obtain proper support from social workers – half of the parents have never had any contact with them. Such cooperation, where it exists, is rated very poorly, especially by fathers, which might result from 'the outside' look or expectations incompatible with reality.

The declared knowledge of fathers about their children's illness was definitely poorer than the knowledge of the mothers, which has also been noted by other authors [3, 13, 16]. For the proper functioning of the whole family and optimized care for the patient, the knowledge of the parents should be similar. Accepting information about the illness at the time of its recognition as being sufficient by most of parents is surprising, and might be the result of falsification of memory. Nowadays, the necessity for obtaining more information about the illness and treatment is indicated. According to the results of the presented study, the information is transferred in understandable way and at an appropriate time. However, the place where conversation takes place should be changed. The medical staff have a big responsibility for providing information which, for almost a half of the parents, is the only source of information. The remaining group mostly use Internet, the easy access to which creates the chance to expand / update the possessed knowledge, but at the same time there is the risk of obtaining false information which might negatively influence the care given to a patient.

CONCLUSIONS

The families of Polish children with CKD require support as far as financial and educational help for school children is concerned; social workers hardly play any role in supporting the children and their families. The discrepancies in evaluating the family situation between the mothers and fathers of ill children, especially assigning to themselves the main role as caregivers, or in the range of social contacts, might be the source of conflicts. The social isolation is most often noticed by the mothers of children on peritoneal dialysis. The relations with medical staff are perceived as good, being rated higher by mothers than by fathers. Despite declaring possession of good knowledge about the illness of their children, the parents report a deficit in information connected with the illness..

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